

Developments, April 2016
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Intro

Developments is a newsletter for Autism CARES legislation grantees, published by AUCD's Interdisciplinary Technical Assistance Center on Autism and Developmental Disabilities (ITAC) in partnership with AMCHP's State Public Health Autism Resource Center (SPHARC). Its purpose is to share news, activities, events, research, and accomplishments across grantee areas - research, training, and state implementation

MCHB Minute

[Update from the Division of MCH Workforce Development](#)

In recognition of Autism Awareness Month, the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau is pleased to share this new infographic that highlights HRSA's investments to advance the goals of the Autism CARES Act. Throughout the month, check HRSA social media channels for tweets, Facebook, LinkedIn and website posts that will share information about the work that you do to train health professionals, advance the evidence-based on effective interventions, and develop state systems of care for children and youth with ASD and other developmental disabilities. [Read more...](#)

[Secretary Burwell Names Dr. Thomas E. Novotny New HHS Autism Coordinator](#)

HHS Secretary Burwell named Dr. Thomas Novotny as the new HHS Autism Coordinator, authorized under the Autism CARES Act of 2014 (see Sec. 2 (a)). Dr. Novotny's duties, according to the law, are to 1) implement autism spectrum disorder activities, taking into account the strategic plan developed by the Interagency Autism Coordinating Committee; and 2) ensure that autism spectrum disorder activities of the Department of Health and Human Services and of other Federal departments and agencies are not unnecessarily duplicative. [Read more...](#)

Training Topics

[OH LEND Students Present Research Outcomes in Joint Poster Symposium](#)

On April 7, the Leadership Education in Neurodevelopmental and related Disabilities (LEND) Program at Cincinnati Children's Hospital Medical Center and the University of Cincinnati (UC) joined with the Ohio State University (OSU) Nisonger Center LEND to host a joint poster symposium for graduating trainees. This 5th annual event offered trainees, faculty, staff and community members - including Jonathan Dever (R), State Representative for the 28th district of the Ohio House of Representatives - the opportunity to explore a wide range of topics impacting Ohioans with disabilities including health insurance coverage, transition to adult healthcare, and community inclusion. Representative Dever cosponsored The Ohio ABLE (Achieving a Better Life Experience) Act in the House of Representatives. [Read more...](#)

Tuberous Sclerosis Complex Autism Center of Excellence Research Network (TACERN) Trains CALEND Fellows in Research, Clinical Skills, and Leadership

The Tuberous Sclerosis Complex Autism Center of Excellence Research Network (TACERN) brings together a group of five children's hospitals located throughout the U.S., all affiliated with LEND interdisciplinary training programs, to conduct research on autism spectrum disorder (ASD) in young children with tuberous sclerosis complex (TSC). The project is funded by NIH/NINDS to conduct a longitudinal study to identify early biomarkers of ASD in infants with TSC, and the Principal Investigators are Mustafa Sahin, MD, from Boston Children's Hospital and Darcy Krieger, MD, from Cincinnati Children's Hospital. A unique aspect of the study is the collaboration with LEND training programs, and a major goal of the project is to work with the affiliated LENDs to improve ASD diagnosis and treatment in TSC and facilitate combined training in ASD and TSC so as to engage ASD researchers in educational and research activities in TSC and vice-versa. [Read More...](#)

Pediatric Audiology Trainees Collaborate with State Division of Public Health to Conduct Statewide Analysis of EHDI Services

LEND trainees from the Carolina Institute for Developmental Disabilities at UNC - Chapel Hill, attended the national EHDI Conference in San Diego, March 13-15, 2016, where they presented a poster entitled: "Regional Analysis of EHDI Outcomes in North Carolina." The EHDI acronym, which stands for Early Hearing Detection and Intervention, represents the systems of care responsible for screening, diagnosis, and intervention for infants with congenital or early onset hearing loss. EHDI programs across the nation have committed themselves to the "1-3-6 goals" of screening infants for hearing loss no later than one month of age with diagnosis no later than three months of age and intervention no later than six months of age. Remarkable progress has been made over the past 20 years since newborn hearing screening has developed into a standard of care but challenges remain, especially with regard to timely diagnosis and intervention. [Read more...](#)

DBP Annual Conference Held in California

The Annual MCHB DBP Faculty and Fellows meeting was co-hosted by Stanford University and University of CA Davis in Palo Alto CA on March 9-11, 2016. The overall goals of the meeting are (1) to allow fellows to present their research projects to other fellows and faculty to get feedback on their projects and (2) to encourage networking among the faculty and fellows. [Read more...](#)

BCH DBP Brings Community Advocacy Rounds to National Conference

At Boston Children's Hospital's Developmental Behavioral Pediatrics Fellowship, we are completing our second year of Community Advocacy Rounds, and taking it on the road! Community Advocacy Rounds is an educational series created for our trainees, focusing on topics most relevant to children with autism and developmental disabilities who are also among underserved populations. For 10-12 afternoons each year, trainees in our Developmental Behavioral Pediatrics Fellowship, Postdoctoral Psychology Fellowship, and LEND Program come together for team based learning. An equally interdisciplinary team (of social workers, psychologists, an educator, and a developmental pediatrician) leads each session. [Read More...](#)

Research Roundup

[AIR-P Activities](#)

The Autism Intervention Research Network on Physical Health (AIR-P), led by Karen Kuhlthau, PhD, conducts research on evidence-based interventions to improve the physical health and well-being of children and adolescents with autism spectrum disorders (ASD) and other developmental disabilities, with an emphasis on underserved communities. Two key goals of the AIR-P network are to provide opportunities to develop collaborations and partnerships with clinicians and researchers and to support junior investigators in developing their research efforts to improve medical care of children with autism. [Read More...](#)

[AIR-B Activities](#)

The first phase of the new grant awarded for the Autism Research Network for Behavioral Health (AIR-B) at UCLA has begun. Partnerships with community agencies have been established at all four sites of AIR-B, Los Angeles, Philadelphia, Rochester and Sacramento. Partners at each site include health and education agencies aimed at serving low income, primarily minority families of children with ASD and other disabilities. For example, in Los Angeles, UCLA researchers have established partnerships with South Central Los Angeles Regional Center (SLARC) and Fiesta Educativa along with a pre-existing partnership with Healthy African American Families (HAAF). [Read more...](#)

[Promoting Healthy Weight in Children and Youth with Autism Spectrum Disorder/Developmental Disabilities: Current Research and Future Directions](#)

Wednesday, May 11, 2016, 1:00 - 4:00 pm ET

Join colleagues for this special symposium focused on research and intervention strategies for encouraging healthy weight in children and youth with ASD/DD. This is a free symposium held in conjunction with the IMFAR on May 11, 2016 in Baltimore, MD. [Read more...](#)

[More about the Cause and Treatment of Tactile Problems in Autism](#)

To further our understanding of abnormal touch/pain responses in children with autism, our group undertook to obtain the first skin biopsies ever reported in autism.* Four children between the ages of 8 and 11 participated in our exploratory study. Biopsies were submitted for specialized evaluation of C-tactile fibers - small tactile nerves mediating pleasant touch, pain, and temperature. Remarkably, results in all four children showed 50% loss of small tactile nerves. This was not a large enough group to be able to explain tactile abnormalities in all children with autism. However, with these four children, results provided an explanation for difficulties with gentle touch involved in daily living, abnormal pain thresholds, and social delay on the basis of tactile loss. Results will be published in the Journal of Neurological Disorders next month [1]. A larger case control study has been initiated. [Read more...](#)

State Stories

[Updates from the State Public Health Autism Resource Center](#)

AMCHP's the State Public Health Autism Resource Center (SPHARC) has several new activities planned, along with presentations, webinars and technical assistance opportunities designed to aid and assist ASD/DD grantees. [Read more...](#)

[New Dynamic Website Focuses on Total Child Health for Iowa's Children and Youth with Special Health Care Needs, their Families, and Providers](#)

The Iowa Regional Autism Assistance Program (RAP) collaborated with Iowa's Systems Integration Grant to create a new robust website, IowaChildHealthConnections.org. This dynamic website focuses on total child health for Iowa's children and youth with a special health care need, their families, and the providers who care for them. [Read more...](#)

Collaborators' Corner

[New CDC Autism Data Highlights Importance of Long-Term Services and Supports, Cultural Competency](#)

The Centers for Disease Control and Prevention (CDC) released data from its Autism and Developmental Disabilities Monitoring Network indicating that 1 in 68 school-aged children are on the autism spectrum. In announcing the rate, which is unchanged from 2014, the CDC called attention to the critical role services and supports play in helping people with autism reach their full potential. [Read more...](#)

[Got Transition Anticipates ACP Pediatric to Adult Care Transition Tools](#)

In May this year, the American College of Physicians (ACP) will be releasing new transition readiness/self-care assessment and medical summary tools modeled after Got Transition's "Six Core Elements of Health Care Transition. The goals of a successful transition from pediatric to adult health care are to ensure continuity of care, exchange of medical information, and engagement of young adult patients in their own care. ACP's initiative offers clinicians a standardized approach to improve care transitions for young adults with specific chronic conditions. New condition-specific transition tools are available, including 1) a transition readiness assessment (for use in pediatric care), a self-care assessment (for use in adult care), and a medical summary/transfer record containing the essential information needed for communication between pediatric and adult clinicians for practices." [Read more...](#)

[CAPTAIN: A Model for Implementing Systems Change](#)

The California Autism Professional Training and Information Network (CAPTAIN) is a statewide network created to support the understanding and use of evidence-based practices (EBPs) for

individuals affected by Autism Spectrum Disorders (ASD). This multi-agency group was established as a result of California's participation in the CDC's Act Early Regional Summit in 2009 where standardized training, dissemination and implementation of EBPs in autism was identified as a priority for the state. With subsequent funding from OSEP's National Professional Development Center for Autism Spectrum Disorders (NPDC - ASD) Training and Technical Assistance Grant in 2010-2012, six demonstration sites throughout the state were trained in the 24 (later 27) EBPs verified by NPDC -ASD to be effective for this population. [Read more...](#)

ITAC Items

[2016 Autism CARES Grantee Virtual Meeting: Integrated, Person-Centered Approaches to Transition](#)

The 2016 Autism CARES Virtual Meeting will be held virtually (i.e. through an online portal) on Thursday, July 21 as a half-day event exploring the topic of transition. This will be an opportunity for MCHB-funded CARES legislation grantees (representing research, training, and state implementation stakeholders) to share information about activities within their respective networks, discuss emerging trends, and facilitate meaningful collaboration. Save the date - registration will open in May and will be available at <http://www.aucd.org/itac/template/index.cfm>

The planning committee is looking for up to 12 grantees to highlight their transition efforts by recording five-minute videos (e.g. PowerPoint slides with audio) that participants will be able to view online before and during the meeting. Presenters will also be expected to facilitate virtual breakout discussions on a transition topic related to their work. Submit your 200-word abstract by Wednesday, April 27 at <https://www.surveymonkey.com/r/HLDFWVB>

[Six Programs That Engage People with Disabilities, Family Members, and Community Professionals Awarded Supplementary Project Funds through AUCD](#)

One essential characteristic of a leader is the constant desire to improve, and training programs that prepare students for leadership roles in the field of developmental disabilities are no exception. The nation's 43 Leadership Education in Neurodevelopmental Disabilities (LEND) and 10 Developmental-Behavioral Pediatrics (DBP) Programs provide long-term, graduate level training to over 3,000 students each year, as well as coordinated, interdisciplinary care to children with special health needs. For more than six decades, LENDs and DBPs have played a leading role in advancing our knowledge of and services for people with disabilities and their families as they teach clinical excellence, model inclusion, work across systems to promote quality services, and advance policy, research and practice. [Read more...](#)

[Diversity and Inclusion Toolkit Update](#)

Recently, AUCD rolled out its Diversity and Inclusion Toolkit. The Toolkit is a website that provides concrete objectives, strategies, and resources to help you realize your goals related to diversity, equity, inclusion, and cultural and linguistic competence. Strategies and resources are aligned with the roles of three specific audiences, one of which, university-based centers, is designed to cater directly to Leadership in Neurodevelopmental and Related Disabilities (LEND)

and University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) programs. [Read more...](#)

Meetings

[HWRN Symposium](#)

May 11, 2016,
1:00 pm - 4:00 pm ET
Baltimore, MD

Registration ends May 1. More information and registration available [here](#).

[The 2016 Autism CARES Grantee Meeting](#)

July 21, 2016
1:00 pm – 4:00 pm ET
Virtual Meeting

Registration will open in May. More information will be available [here](#).

AUCD 2016 Conference

[Navigating Change: Building Our Future Together](#)

December 4-7, 2016
Washington, DC

More information will be available [here](#).

Upcoming Webinars

[Emergency Preparedness for Individuals with ID/DD](#)

Tuesday, April 26, 2016
1:00 pm - 2:00 pm ET

This webinar emphasizes emergency preparedness for individuals with intellectual, physical and sensory disabilities, their families and support networks. [Read more...](#)

[Advancing Sexual Self-Advocacy for People with Disabilities](#)

Thursday, April 28, 2016

3:00 pm - 4:00 pm ET

Findings from an exploratory study that examined how people with intellectual and developmental disabilities define and experience the concept of sexual self-advocacy will be discussed. [Read more..](#)

About

Developments is a newsletter for Autism CARES programs funded under MCHB. The content of this newsletter has been generated by program staff and trainees, and does not necessarily reflect the views and policies of HRSA-MCHB. No official support or endorsement by HRSA-MCHB is intended or should be inferred. This publication is funded in part by cooperative agreement #UA5MC11068.